



# Expanded Guide for Caregivers and Care Partners

# Luminis Health Expanded Guide for Caregivers and Care Partners

A Caregiver or Care Partner is a family member or friend who has been identified by a patient to participate as an important member of the health care team, **TOGETHER** with the doctors, nurses, other staff, and the person that you care for, the patient.

We will be using the terms Caregiver and Care Partner interchangeably throughout this document, to encourage the participation and insights of family or friends who have been asked to participate with one of our patients in their care and healthcare decision making processes. The staff at Luminis Health understand that Caregivers and Care Partners provide an invaluable support system and continuity of care for our patients as you walk alongside them in their healthcare journey, and we are eager to work together to optimize the healthcare outcomes for the person you care for.

We invite you to participate in the role of care partner in ways that are comfortable to both you and the patient—whether you are simply present, or if you are participating in care and helping to make decisions. We encourage you both to collaborate **TOGETHER** with the health care staff, using recommendations on the following page as appropriate.





**Talk about your role** with the person you care for. Introduce yourself to staff and describe your relationship to the patient and how you'd like to participate in their care.

**Observe changes** (physical, behavioral, emotional) in the patient and report them to health care providers. Ask staff what observations they would like you to routinely share.

**Gather helpful information** (current medications, medical history, other health care providers, and insurance) and bring it all to the hospital.

**Ensure that you're present**, if possible, at times when information will be shared and decisions need to be made. Keep your schedule for coming to the hospital manageable. Let staff members know how to reach you and be sure you know whom to contact for information when you're away from the bedside.

**Tell staff if you have any concerns** about the patient's condition or safety or if you are uncomfortable because "something just doesn't feel right."

**Help with decision-making** about care and treatment. Be a second set of eyes and ears for the patient. Ask questions and take notes. Encourage the patient's participation in decision-making to the extent they choose.

**Enlist help from staff members** with whom you are comfortable so that they can support you both as you participate in care and decision-making.

**Ready yourself for transitions** to home or community care. Before you leave the hospital, make sure your questions and those of the patient have been answered. Know what will be needed afterwards (medications, treatment, equipment, follow-up appointments) and what changes in the patient's condition should be reported to health care providers.

### Talk about your role...

Hospitals like ours recognize that patients define “family” in various ways. Even if you are not biologically or legally related to the patient, he/she has identified you as having a special relationship as a Caregiver or Care Partner.

- What is your relationship to the patient? How long have you known them?
- What authority do you have to make decisions for the person you care for, if needed (i.e., health care agent or power of attorney)?
- What is your interaction with other family members? Will you be the patient’s main spokesperson and how will information be communicated to other family members?
- Before this hospitalization, what medical or health-related activities did you engage in with the patient? What kind of care did you provide?
- What care does the patient want you to provide in the hospital?
- What care are you comfortable providing (getting beverages and/ or food, assisting with getting to the bathroom or walking in the hall, helping with physical therapy, asking questions)?
- Do you know the names and roles of various staff members? Have you had an opportunity to talk to them about how you can work together?



### Observe changes in the patient...

As a family member or friend, you know what is normal for the person that you care for outside the hospital setting—physical appearance, level of activity, typical behavior, or emotions. Any noticeable changes could be important indicators of health status and would be helpful to share with staff. For example, does the person:

- Look different to you (paler, more flushed, out of breath, unsteady when walking)?
- Seem to be behaving differently (more/less talkative, more/less active, more withdrawn, anxious, agitated, or confused)?
- Seem uncomfortable or in pain? How can you tell?
- Show noticeable changes in appetite, toileting, or other daily activities?



### Gather helpful information...

**As much as possible, make sure you are aware of important information about the patient and where certain documents are located in case they are needed.**

- What significant medical conditions, treatments, and medications has the patient had before?
- Has the patient been hospitalized before? When, where, and why?
- Who are his/her/their doctors outside the hospital? What is their contact information?
- What insurance do they have? If there is more than one insurance company, do you know which is primary and secondary?
- Who has financial/health care power of attorney?
- Is there a living will/advance directive?

### Ensure that you're present at important times...

**Together with the person you care for, you will decide when it's best for you to be at the hospital, especially when important information will be shared.**

- Based on your own schedule (work, home responsibilities), when is the best time for you to be with the patient on a regular basis?
- Does the patient want you to be there at particular times (mealtime, before bedtime, during tests or procedures)?
- Based on your schedule, when can you interact regularly with doctors and other staff about treatment and care? When will key doctors see the patient? What time are rounds (when doctors and other staff discuss the patient's progress and care plan, treatments, and tests)? How might you participate?
- What time are nursing change of shift reports (when a nurse shares information about a patient with oncoming nurses and informs them about progress or changes in a patient's condition or care)? How might you participate?
- In addition to the patient's chart, is there an appropriate place (white board in the room) where you can leave your contact information (cell number, work number) and your daily schedule for staff?
- When will important diagnostic tests (lab work, CT scan) be scheduled? When will staff discuss the results with you both?

### **Tell staff, if you have concerns...**

**Because you are a Care Partner, don't hesitate to ask or comment if something happens that doesn't make sense or doesn't feel right to you or the patient.**

- Have you received information from staff members that seems different or contradictory?
- Has there been a sudden, unexplained change in medications, treatment, or therapy?
- Has the patient been told he/she will have a diagnostic test without being told why?
- Did a new staff member come to provide care and seem uncertain about the medical history and treatment?
- Has the person you care for received timely help for position changes (in bed, from chair to bed) and have call bells been answered in a timely way?

### **Help with decision-making...**

**As members of the health care team, patients and their Care Partners will be asked to participate in decision-making about care and treatment, along with doctors, nurses, and other staff. Staff may present information and options which may be unfamiliar to you. Don't hesitate to ask questions, to take notes, and to say that you and the patient need more time to consider.**

- Have you been asked about your preferences related to care—and has that information been included in the care plan?
- How can you provide regular input as the care plan is revised?
- After important diagnostic tests (lab work, CT scan), when will staff discuss the results with you both? What do the results suggest for care and treatment?
- Have the risks, side effects, and benefits of different treatment options been clearly explained so that you both have the information to make decisions?
- How have you and the person you care for made important decisions in the past, especially about health care? Who else have you involved in decision-making?
- If either of you are unsure about a proposed treatment plan, who else can give you additional medical advice—your primary care doctor, other specialists?



### Enlist help from staff members...

**As a caregiver and member of the health care team, it's important that you feel comfortable in your role, as you and the person you care for have defined it. Feel free to participate as much or as little as you want on any given day. When participating in care, ask for advice if you need it.**

- Do you feel comfortable asking questions and expressing concerns about the patient's condition or treatment?
- Have you and staff members talked about how you can partner together in care?
- Together with staff members, have you identified new ways you might participate in care and what information might make you feel more confident and comfortable in your role as caregiver?

### Ready yourself for transitions...

**Although everyone wants to leave the hospital, the prospect can be intimidating for the patient and for you as a caregiver. It's normal to have many questions at this time, and it's crucial that you get the answers you need, before leaving the hospital.**

- Have there been any discussions about getting ready to go to another unit in the hospital or a different facility (physical rehabilitation center, or home or community care), even if this transition is far in the future?
- Have you discussed preferences and concerns related to transitioning with the discharge planner, doctors, nurses, or other staff?
- Do you know what the patient will be able to do independently at home or in community care? Are there restrictions on foods or types of activities?

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**Is it clear what will be needed at home or in community care:**

Medications or special nutrition? \_\_\_\_\_  
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Equipment (walker, chair for shower, oxygen)? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

Professional services (nurse or nursing assistant, physical therapy, occupational therapy)? \_\_\_\_\_  
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Follow-up visits with the primary care doctor and/or specialists? \_\_\_\_\_  
\_\_\_\_\_  
\_\_\_\_\_

**Have you and the person you care for been given a written summary of the discharge plan and reviewed it with a staff member? Have all of your questions about discharge instructions been answered?**

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**Based on the patient's needs and your schedule and other responsibilities, what care can you reasonably provide at home? What other help might be needed and who can help you find it?**

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**Do you both know what symptoms or signs to be watching for to determine whether you need to call the doctor?**

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**After you leave the hospital, if you have concerns or questions, do you both know whom to call?**

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**Notes:** \_\_\_\_\_  
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